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Cultural Epidemiology: Conceptual Framework and Current Directions of an Interdisciplinary Field

Cultural epidemiology is an interdisciplinary field based on principles and methods of medical anthropology and classical epidemiology. Its contribution to health research results from a focus on illness, distinct from the disease orientation of classical epidemiology. Though rooted in the influential illness explanatory model framework, current developments in the field of cultural epidemiology refer more explicitly to determinants of health and illness beyond explanatory models based on frameworks of critical medical anthropology. This rethinking of cultural epidemiology acknowledges the need for research to consider domains of a revised Outline for Cultural Formulation referring to cultural identity, key social relations, and the impact of political economy and other structural features of society. In addition to this current work in cultural psychiatry, two other areas of research remain active: public health studies of professional and community determinants of vaccine acceptance and research on assessment and study of stigma as a clinically significant feature of illness experience, providing a clinical complement to more mainstream community studies of stigma.

Key words: cultural epidemiology, illness and disease, illness explanatory models, stigma, vaccine acceptance, Outline for Cultural Formulation

Културна епидемиологија: концептуални оквир и актуелни правци интердисциплинарног поља

Културна епидемиологија је интердисциплинарно поље засновано на принципима и методима медицинске антропологије и класичне епидемиологије. Њен допринос истраживањима здравља исходи из усредсређености на концепт болести, који је другачији од концепта обољења, ка коме се оријентише класична епидемиологија. Иако укорени у оквиру утицајног експланаторног модела болести, савремени токови на пољу културне епидемиологије експлицитније реферишу на детерминанте здравља и болести које превазилазе експланаторне моделе базиране у оквирима критичке медицинске антропологије. Овакво преиспитивање културне епидемиологије признаје да постоји потреба да истраживања узму у обзир делове ревидираног Нацрта за културно формулисање који се односе на културни идентитет, кључне друштвене односе, утицај политичке економије и других структурних одлика друштва. Поред постојећег рада на пољу културне психијатрије, још су две истраживачке области активне: истраживања професионалних и друштвених детерминанти прихватања вакцинације у оквиру јавног здравља; истраживања на процени стигме као клинички

значајне инстанце за искуство болести која доприносе креирању клиничке допуне за више мејнстрим друштвена истраживања стигме.

Кључне речи: културна епидемиологија, болест и обољење, експланаторни модел болести, стигма, прихватање вакцина, Нацрт за културно формулисање

Background

Conceived as an interdisciplinary field, cultural epidemiology developed a framework and methods based on principles and practices of medical anthropology and classical epidemiology. Cultural epidemiology has been defined as the study of locally valid representations of illness and their distribution. These representations are elaborated by variables and narrative description with reference to illness experience, perceived causes of illness and illness behaviour. The integration, not just mixing, of quantitative epidemiological methods and qualitative ethnographic methods is a priority, and specialized techniques have been developed for that (Mitchell G. Weiss 2001; 2017). A fundamental principle of medical anthropology, acknowledging the distinction of *disease* and *illness*, is central to the rationale and definition of cultural epidemiology.

This distinction of disease and illness, which has become a fundamental principle on which medical anthropology and cultural epidemiology are grounded, arose from disenchantment with the technological and increasingly industrial orientation of medical practice in the United States in the 1970s. Much of the work in the early development of medical anthropology, responding to practical needs and academic interests, was a product of clinical experience of anthropologists and clinician-anthropologists (Chrisman and Maretzki 1982). John Cassell, a practicing internist and public health researcher, initially developed and elaborated the distinction of illness from disease based on concerns about public dissatisfaction with medical care and the realization that the most significant improvements in the health of populations could not be explained as a simple product of technological advances enabling improved clinical treatment of disease. He also argued that the focus on disease in medical training was a source of later frustration for doctors after they left academic training and began to practice medicine. The focus on disease left them unprepared to respond to patients' concerns about their illnesses. Furthermore, he regarded the assumption that illness and disease are the same as a cultural artefact, and he reasoned that curing and healing were therefore different functions as well. He explained this proposition in a 1976 paper as follows:

There is a distinction between the disease of an organ of the body and the illness of the whole man. We certainly base many of our complaints about doctors on just such a difference. We say, "All the doctor seems to care about are my kidneys; he doesn't care about me"—and we know what we mean, or think we do. From this point on, let us use the word "illness" to stand for what the patient feels when he goes to the doctor and "disease" for what he has on the way home from the doctor's office. Disease, then, is something an organ has; illness is something a man has. (Cassell 1976, 27)

Over time, this distinction has been refined with regard to theory in medical anthropology without fundamentally altering the point (Hahn 1984). In current usage, disease has become a proxy for broader professional considerations beyond the “disease of an organ of the body” to also include biochemical processes, injuries and other professionally conceived explanations of health problems as disorders.

Definitions of classical epidemiology as a basic science of public health typically refer to the occurrence and determinants of disease in a population. Although nontechnical definitions of epidemiology refer to the study of the causes, distribution and control of *disease* in populations, technical accounts are more careful to make broader professional interests explicit, expanding the concept of disease to “health-related states or events in specified populations, including the study of the determinants influencing such states, and the application of this knowledge to control the health problems” (Porta 2014). The WHO definition glosses “health-related states or events” as “diseases” in its online definition.

Cultural epidemiology should be distinguished from classical epidemiology insofar as it is an epidemiology of illness—not an epidemiology of disease, disorder or other entity derived from professionally defined systems of classification. It is concerned with the illness-related experience, meaning and behaviour from the vantage point of the people directly concerned (including patients) or otherwise involved (e.g., family, colleagues, community and caretakers). The epidemiology of tuberculosis as a disease is a different matter from the cultural epidemiology of TB illness. As Cassell (1976, 32) pointed out in his classic account noted above, “in tuberculosis, where the disordered feelings, disconnectedness from the society, and numerous other ramifications of the disease are widespread and pervasive, curing—killing the tubercle bacillus—represents only part of returning the patient to health”. Measuring the incidence and prevalence of TB does not tell us how common the features of illness actually are, or whether such problems among the patterns of distress explain why people wait too long before coming for treatment or fail to complete their prescribed treatment. Such questions are matters that the methods of cultural epidemiology are better able to consider.

The instruments and approach of cultural epidemiology were initially conceived in the Harvard medical anthropology programme in the 1980s, where the framework of Kleinman’s illness explanatory models and motivating interest in cultural psychiatry were highly influential (Kleinman 1980, 1977). Developed with research partners, the instruments were explanatory model interviews. Because they were concerned with locally meaningful accounts of illness, rather than professionally valid accounts of disease, the concepts and categories that were counted had to be adapted according to the cultural setting and particular health problems to be studied. Categories for coding perceived causes in a study of childhood diarrhoea in Central Thailand concerned with use of oral rehydration solution were necessarily different from suitable categories for an interview intended for research on patients with depression in India. An adaptable framework, however, enabled categorical coding for quantitative analysis of responses to questions about illness experience, perceived causes and help seeking. The interview was also designed to elicit extensive narrative accounts of illness and study-specific interests for qualitative analy-

sis. A set of analytic methods were developed to relate qualitative and quantitative data using software available at the time and enhanced over the years, most recently using tablet devices for recording and time stamps for first-level qualitative coding (Giduthuri et al. 2014).

Respondents' *emic* account of illness that are the focus of cultural epidemiological study may be contrasted with *etic* data grounded in professional disease explanatory models. The instruments based on that framework were commonly called EMIC interviews (Explanatory Model Interview Catalogue), referring both to the priority of their *emic* orientation and acknowledgement that such interviews were adapted and collectively constitute a catalogue rather than a single fixed instrument. Conceived in the framework of clinical medical anthropology, these EMIC interviews were tools for studying the cultural epidemiology of illness explanatory models, providing useful information that complemented findings from both classical epidemiology and more extensive ethnographies based on traditional anthropological methods. The approach to development of EMIC interviews was firmly rooted in Kleinman's illness explanatory model framework, based on "notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (Kleinman 1980, 105).

For clinician anthropologists, explanatory models were especially appealing because they were concerned with the way culture affected individuals with particular problems, instead of presenting a homogenized view of patients based on reference to a simplistic set of cultural characteristics that might too easily replace the individuality of patients with a stereotype. Cecil Helman was a general practitioner in North London and an anthropologist who taught in a graduate programme. He authored an influential textbook of medical anthropology in which he made the point that "one cannot make broad generalizations about the members of any human group without taking into account the fact that differences among the group's members may be just as marked as those between the members of different cultural groups" (Helman 2007, 4). A patient-centred explanatory model approach, focusing on illness episodes, was well-suited for enabling use of anthropological insights in clinical practice. Cultural epidemiology provided a means of documenting patterns of illness that both clarified ethnomedical concepts of a study group and enabled study of practical implications.

To explain its theoretical grounding and motivation for further developing the approach, it is important to acknowledge the two branches of medical anthropology that began developing in parallel in the 1970s. Both were concerned with limitations imposed by the dominant disease models and practices in biomedicine and the health systems they were a part of. In contrast to explicit clinical and public health priorities that medical anthropology was contributing to, another approach was also emerging, closer to traditional anthropological study of medical practices and health systems with a focus on the health impact of political and economic structural features of society. This critical medical anthropology (CMA) was initially conceived as an approach to transcend microanalytic study interests and pursue an alternative based on macroanalytic considerations. Although explanatory models were relevant for microanalytic studies of illness episodes, CMA study of health

systems relied on conceptual frameworks based on political economy, equity and questions of power and access to resources (Janzen 1978; Baer, Singer, and Johnsen 1986; Singer, Baer, and Lazarus 1990). The explanatory model framework was acknowledged as inadequate to address such questions (Kleinman 1997).

Topical interests of the field

Recent reviews of cultural epidemiology and explanatory models in psychiatry provide an overview of topical interests with particular attention to research on cultural psychiatry and mental health topics (Mitchell G. Weiss 2018; 2017). They refer to studies in India of depression, schizophrenia, neurasthenia and suicide. The research includes clinical ethnographic accounts elaborating ethnomedical concepts of mental illness (Mitchell G. Weiss et al. 1988), and considers their relationship to psychiatric diagnoses (M.G. Weiss, Raguram, and Channabasavanna 1995). Cultural epidemiological study of family survivors of suicide suggested the value of a sociocultural autopsy based on the EMIC framework to complement current mainstream approaches to psychological autopsy that overemphasize the explanatory value of psychiatric diagnoses at the expense of social relationships and societal structural factors (Parker, Nagarsekar, and Weiss 2009). Stigma has been an enduring interest of cultural epidemiology (Raguram et al. 2004).

Infectious disease studies highlight a set of research interests that were already clear from the outset. In fact, the first EMIC interview was developed for a study of leprosy and mental health, and it examined illness explanatory models of people with leprosy in Mumbai (M.G. Weiss et al. 1992). Cultural epidemiological studies of TB have examined the role of gender differences in the experience (patterns of distress) and meaning (perceived causes) of TB in a group of studies in Bangladesh, India, Malawi and Colombia (M.G. Weiss et al. 2008), and effects of features of illness explanatory models that account for delayed help seeking (Gosoni et al. 2008). Studies of TB-related stigma have considered both community views and the experience of patients (Atre et al. 2011; Somma et al. 2008). Additional cultural epidemiological studies of infectious diseases have focused on other neglected tropical diseases, including leprosy and Buruli ulcer.

Current activities and next steps

Three areas of current research are extending the scope and framework of cultural epidemiological principles and methods. Topics include studies of vaccine acceptance based on awareness, priority and use with a focus on both health care providers and community residents. This work is based on vaccine acceptance and anticipated acceptance studies of oral cholera vaccine in Zanzibar, Kenya and DR Congo (Schaetti et al. 2013; Sundaram et al. 2016), and a study of influenza vaccine acceptance during the 2009 influenza pandemic in Pune, India (Sundaram et al. 2015). More recently, a study of influenza vaccination of pregnant women to protect them and their newborn infants has been developed for WHO. Unique chal-

lenges of limited vaccine coverage with HPV vaccine for adolescents indicate prospects for further study.

Health-related stigma has become an important topic in public health. Most research, however, studies stigmatizing views in communities towards stigmatized diseases. Mental health problems, leprosy, HIV/AIDS and TB are common examples. The near-exclusive focus of research on stigma in the community, however, ignores relevant aspects of stigma in the clinic. Our work suggests that experience and concerns with clinically significant stigma should become a more regular consideration in the course of clinical assessment. Distinguishing the impact of experience as a target of previously enacted stigma from currently anticipated and ongoing self-stigmatization is a relevant consideration for study of clinical stigma (Mitchell G. Weiss 2008). Methods for analysing, documenting and comparing the magnitude of stigma and qualitatively assessing stigma narratives have been refined to improve prospects for comparing stigma assessments. Such clinical stigma studies are needed to complement well-established community stigma research in the fields of sociology, social psychology and population-based studies in psychiatry that support anti-stigma campaigns. A focus on clinically significant stigma overcomes limitations of labelling-based formulations by applying principles of cultural psychiatry to study of illness experience, which includes experience of stigma.

Development of the Outline for Cultural Formulation (OCF) for psychiatric assessment in the DSM-IV represented an important contribution of cultural psychiatry to clinical assessment (American Psychiatric Association 1994). Although experience with the OCF has been limited to psychiatry, the framework is relevant for other areas of medical practice and research. A recently proposed revision of the OCF based on experience of our cultural epidemiology research group extends the scope of clinical medical anthropological considerations (Paralikar, Deshmukh, and Weiss In Press). This revised OCF provides an appropriate guide for clinical assessment and for cultural epidemiological research to support use of the OCF. The following is the proposed revised structure: cultural identity (domain I); illness explanatory model (domain II); key social interpersonal relations (domain III); and relevant societal structural features acknowledging the potential impact of social status and political economy (domain IV). This revision is mindful of the potential value of attending to clinically significant issues beyond both disease and illness as a feature of both clinical assessment and research. Further research in cultural epidemiology should be more explicit in their attention to domains I, III and IV of this formulation to support documentation and use of the revised OCF. This will thereby enable needed attention not only to health problems but also to the person, social stressors and supports, and the opportunities and constraints imposed by structural features of society.

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